



Letter to the Editor

Talking about “psychogenic nonepileptic seizure” is wrong and stigmatizing



To the Editor,

Over the last few years *Seizure - European Journal of Epilepsy* has published many articles on Psychogenic Nonepileptic Seizures (PNES). For example, six articles with “PNES” in their title were identified since January 2019, i.e. in the last five months [1–6]. “PNES” is now the most common term in the neurology literature for naming a psychiatric disorder characterized by the production of clinical seizures without electroencephalographic changes. This disorder has been misnamed over the centuries with different terms, such as “hystero-epilepsy,” “pseudo-seizures,” etc., that were either wrong, stigmatizing, offensive or denied the reality of the symptoms. Despite an apparent consensus to properly name the disorder, the recent psychiatric classification system DSM-5 proposed two different alternatives: “conversion disorder” (CD) or “functional neurological symptom disorder with attacks or seizures” (FNSDa) [7]. “Conversion disorder” referring to a psychoanalytic hypothesis was largely debated [8] and this term is now poorly used in the modern neurological and psychiatric literature.

Here, we would like to stress not only why using “PNES” repeats the errors of the past by being wrong and stigmatizing but also how it hampers the progress of research in the field and the needed collaboration between neurologists and psychiatrists.

1. “Psychogenic” is wrong

“Psychogenic” means that FNSDa originates “in mind”, with a psychological etiology. The term refers to a dualistic representation of disorders (somatogenic vs psychogenic) and implies the absence of an organic substratum. In a much more modern representation, psychological phenomena are considered to be brain-related and may contribute to the expression of “somatogenic disorders”. There are now some pathophysiological data identifying structural and functional brain correlates of FNSDa [9], leading us to consider biopsychosocial models for understanding this disorder. The presence of psychological factors has been removed in the DSM-5 primary diagnostic criteria [7] since psychological factors have not been shown to be either diagnostically reliable or predictive of outcome [10]. Although psychological factors are identified for the majority of patients, they are not for all and it is not clear whether they are etiologically relevant [10].

2. “Psychogenic” is stigmatizing

This term is poorly accepted by patients as previously shown [11]. In general, it seems that terms assuming an “in mind” etiology, such as “in the mind,” “hysterical” and “psychosomatic” may be offensive to patients [12]. In contrary, the term “functional” was deemed less offensive and more acceptable [12].

3. “Nonepileptic” is meaningless and rejecting

It is remarkable to define a disorder by the disorder it is not. Negative terms, such as “nonepileptic”, provide no relevant information regarding the disorder. This is particularly true when diagnosing “nonepileptic seizure” in patients who never thought they had epilepsy. For example, “pseudosyncope”, one of the most frequent semiologic presentation of FNSDa [13], is characterized by a repetitive loss of responsiveness, which may be poorly evocative of epilepsy. Announcing a “nonepileptic” seizure in individuals without the fear or belief of having an epileptic disorder may seem surprising, even absurd. Furthermore, a negative diagnosis, i.e., one of elimination, is poorly accepted by patients, whereas a positive diagnosis may help one to accept the disorder and its treatment and to avoid any iatrogenic downward spiral [14,15]. Although the diagnostic approach of FNSDa is usually now a positive one, the term “nonepileptic” refers to a diagnostic procedure of exclusion. Finally, one could feel rejected by epileptologists diagnosing a “nonepileptic” disorder.

Exercising rigor with regard to the terms that we use will teach our students and colleagues a new representation of the disorder, one that is more accurate, more respectful and more modern. Furthermore, there is a need for neurologists and psychiatrists to refer to the same terminology, as that is a prerequisite for working together to take care of our common patients and for promoting research in the field. Since PNES may be poorly accepted by patients and is an inaccurate description of the clinical phenomenon, DSM-5 terminology may represent an interesting alternative.

Conflict of interest

None.

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